No. 84-1529

Supreme Court, U.S.
FILED
AUG 30 1985
JOSEPH F. SPANIOL, JR.
CLERK

IN THE

Supreme Court of the United States

OCTOBER TERM, 1985

MARGARET M. HECKLER, SECRETARY OF HEALTH AND HUMAN SERVICES,
Petitioner,

v.

AMERICAN HOSPITAL ASSOCIATION, *et al.*,
Respondents.

On Writ of Certiorari to the United States Court of Appeals for the Second Circuit

---

BRIEF OF AMERICAN ASSOCIATION ON MENTAL DEFICIENCY, THE ASSOCIATION FOR PERSONS WITH SEVERE HANDICAPS, AMERICAN ASSOCIATION OF UNIVERSITY AFFILIATED PROGRAMS FOR THE DEVELOPMENTALLY DISABLED, NATIONAL REHABILITATION ASSOCIATION AS *AMICI CURIAE* IN SUPPORT OF PETITIONER

JAMES W. ELLIS *
RUTH A. LUCKASSON
1117 Stanford, NE
Albuquerque, New Mexico 87131
(505) 277-2146
Counsel for Amici Curiae

Of Counsel:
H. RUTHERFORD TURNBULL, III

* Counsel of Record

WILSON - EPES PRINTING CO., INC. - 789-0096 - WASHINGTON, D.C. 20001

BEST AVAILABLE COPY

TABLE OF CONTENTS

	Page
INTEREST OF AMICI CURIAE	1
SUMMARY OF ARGUMENT	3
ARGUMENT:	
I. CONGRESS HAS RECOGNIZED THAT MODERN DEVELOPMENTS IN MEDICINE, EDUCATION, HABILITATION, AND OTHER SERVICES FOR NEWBORNS AND THEIR FAMILIES HAVE GREATLY ENHANCED THE LIVES OF HANDICAPPED PEOPLE	4
II. PREDICTIONS ABOUT THE FUTURE "QUALITY OF LIFE" OF INDIVIDUAL NEWBORNS ARE NOT UNIQUELY MEDICAL JUDGMENTS IMMUNE FROM CIVIL RIGHTS LAWS	12
III. FEDERAL CIVIL RIGHTS ENFORCEMENT IS AN APPROPRIATE RESPONSE TO THE PROBLEM OF DISCRIMINATION AGAINST HANDICAPPED INFANTS	21
CONCLUSION	24
APPENDIX	1a

TABLE OF AUTHORITIES

CASES: Page

Board of Education v. State, 47 Ohio App. 417, 191 N.E. 914 (1934) 7

City of Cleburne v. Cleburne Living Center, 105 S. Ct. 3249 (1985) 4, 6, 15

Guardianship of Phillip B., 139 Cal. App. 3d 407, 188 Cal. Rptr. 721 (1983) 11

In re Conroy, 98 N.J. 321, 486 A.2d 1209 (1985) .. 18

Jones v. United States, 463 U.S. 354 (1983) 19

Morton v. Mancari, 417 U.S. 535 (1974) 22

Pennhurst State School & Hospital v. Halderman, 465 U.S. 89 (1984) 10

Pennsylvania Association for Retarded Children v. Commonwealth of Pennsylvania, 334 F. Supp. 1257 (E.D. Pa. 1971), 343 F. Supp. 279 (E.D. Pa. 1972) 7

State ex rel. Beattie v. Board of Education, 169 Wis. 231, 172 N.W. 153 (1919) 7

Superintendent of Belchertown State School v. Saikewicz, 373 Mass. 738, 370 N.E.2d 417 (1977) 18

United States v. Turkette, 452 U.S. 576 (1981) 23

Watson v. City of Cambridge, 157 Mass. 561, 32 N.E. 864 (1893) 7

Watt v. Alaska, 451 U.S. 259 (1981) 22

Youngberg v. Romeo, 457 U.S. 307 (1982) 8, 10, 19

STATUTES:

Child Abuse Amendments of 1984, Pub. L. No. 98-457, 98 Stat. 1749 *et seq.* 22, 23

Developmentally Disabled Assistance and Bill of Rights Act, 42 U.S.C. § 6000 *et seq.* 4

Education of the Handicapped Act, 20 U.S.C. § 1400 *et seq.* 4, 7

Rehabilitation Act of 1973 § 504, 19 U.S.C. § 794 .... *passim*

LEGISLATIVE MATERIALS:

119 Cong. Rec. 10802 (1973) 5

119 Cong. Rec. 24568 (1973) 5

121 Cong. Rec. 25540 (1975) 22

TABLE OF AUTHORITIES—Continued

Page

S. Rep. No. 318, 93d Cong., 1st Sess. 8, *reprinted in* 1973 U.S. Code Cong. & Ad. News 2076, 2082 4

S. Rep. No. 168, 94th Cong., 1st Sess. 9, *reprinted in* 1975 U.S. Code Cong. & Ad. News 1425, 1433.. 5, 6

OTHER AUTHORITIES:

Books:

American Academy of Pediatrics Task Force on Pediatric Education, *The Future of Pediatric Education* (1978) 14

American Association on Mental Deficiency, *Classification in Mental Retardation* (H. Grossman ed. 1983) 9

The Association for Persons with Severe Handicaps, *Legal, Economic, Psychological and Moral Considerations on the Practice of Withholding Medical Treatment from Infants with Congenital Defects* (TASH Monograph #1, 1984) 2

Baumeister & Rollings, *Self-Injurious Behavior,* in 8 *International Review of Research in Mental Retardation* 1 (N. Ellis ed. 1976) 9

G.T. Bellamy, D. Horner & R. Inman, *Vocational Habilitation of Severely Retarded Adults: A Direct Service Technology* (1979) 10

Bellamy, Sowers & Bourbeau, *Work and Work-Related Services: Postschool Options,* in *Systematic Instruction of the Moderately and Severely Handicapped* 490 (M. Snell 2d ed. 1983).. 10

Bricker, *Early Communication: Development and Training,* in *Systematic Instruction of the Moderately and Severely Handicapped* 269 (M. Snell 2d ed. 1983) 9

Campbell, *Basic Considerations in Programming for Students with Movement Difficulties,* in *Systematic Instruction of the Moderately and Severely Handicapped* 168 (M. Snell 2d ed. 1983) 9-10

TABLE OF AUTHORITIES—Continued

Page

K. Casey, J. McGee, J. Stark & F. Menolascino, *A Community-Based System for the Mentally Retarded: The ENCOR Experience* (1985) 10

J. Conroy & V. Bradley, *Pennhurst Longitudinal Study: A Report of Five Years of Research and Analysis* (Temple Univ. & Human Services Research Inst. Mar. 1985) 10

R. Darling, *Families Against Society* (1979) 15

Deinstitutionalization and Community Adjustment of Mentally Retarded People (R. Bruininks, C.E. Meyers, B. Sigford & K.C. Lakin eds. 1981) 10

Down Syndrome: Advances in Biomedicine and the Behavioral Sciences (S. Pueschel & J. Rynders eds. 1982) 20

R. Foxx & N. Azrin, *Toilet Training the Retarded* (1973) 8

R. Gaylord-Ross & J. Holvoet, *Strategies for Educating Students with Severe Handicaps* (1985) .. 8

Hollis, *Analysis of Rocking Behavior*, in *Quality of Life in Severely and Profoundly Mentally Retarded People: Research Foundations for Improvement* 1 (C.E. Meyers ed. 1978) 9

N. Hunt, *The World of Nigel Hunt: The Diary of a Mongoloid Youth* (1967) 20

Johnson, *Discussion on the Care of the Feeble-minded and the Epileptic*, in *Proceedings of the National Conference of Charities and Corrections* 410 (1901) 6

J. Jones, *Bad Blood: The Tuskegee Syphilis Experiment* (1981) 17

Kuntz, Carrier & Hollis, *A Nonvocal System for Teaching Retarded Children to Read and Write*, in *Quality of Life in Severely and Profoundly Mentally Retarded People: Research Foundations for Improvement* 145 (C.E. Meyers ed. 1978) 9

Life-Threatening Behavior: Analysis and Intervention (J. Hollis & C.E. Meyers eds. 1982) 9

TABLE OF AUTHORITIES—Continued

Page

D. MacMillan, *Mental Retardation in School and Society* (2d ed. 1982) 11
S. McClennen, R. Hoekstra & J. Bryan, *Social Skills for Severely Retarded Adults: An Inventory and Training Program* (1980) 9
McDonald, *Design and Application of Communication Boards*, in *Non-vocal Communication Techniques and Aids for the Severely Physically Handicapped* 105 (G. Vanderheiden & K. Grilley eds. 1975) 9
Personnel Training Program for the Education of the Severely Handicapped, *Educational Technology for the Severely Handicapped: A Comprehensive Bibliography* (1975) 7
President's Committee on Mental Retardation, *Mental Retardation: The Leading Edge—Service Programs That Work* (11th Annual Report to the President 1979) 10
Rusch, *Competitive Vocational Training*, in *Systematic Instruction of the Moderately and Severely Handicapped* 503 (M. Snell 2d ed. 1983) .. 10
W. Sailor & D. Guess, *Severely Handicapped Students: An Instructional Design* (1983) 8, 11
P. Starr, *The Social Transformation of American Medicine* (1982) 13
Systematic Instruction of the Moderately and Severely Handicapped (M. Snell 2d ed. 1983) 7
Teaching the Severely Handicapped (N. Haring & L. Brown eds. 1976) 8
Thompson, Wilcox & York, *The Federal Program for the Severely Handicapped: Historical Perspective, Analysis and Overview*, in *Quality Education for the Severely Handicapped* 1 (B. Wilcox & R. York eds. 1980) 5
H.R. Turnbull & A. Turnbull, *Parents Speak Out: Then and Now* (2d ed. 1985) 15
G. Van Etten, C. Arkell & C. Van Etten, *The Severely and Profoundly Handicapped: Programs, Methods, and Materials* (1980) 8

TABLE OF AUTHORITIES—Continued

Page

P. Williams & B. Shoultz, *We Can Speak for Ourselves: Self Advocacy by Mentally Handicapped People* (1984) 21

Articles:

Affleck, *Physicians' Attitudes Toward Discretionary Medical Treatment of Down's Syndrome Infants*, 18 Mental Retardation 79 (1980) 17

Alexander, *Medical Science Under Dictatorship*, 241 New Eng. J. Med. 39 (1949) 6

Azrin & Armstrong, *The "Mini-meal"—A Method for Teaching Eating Skills to the Profoundly Retarded*, 11 Mental Retardation 9 (1973) 8

Baer, *The Half-Told Story of Baby Jane Doe*, Colum. Journalism Rev. 35 (Nov./Dec. 1984) 20

Banerdt & Bricker, *A Training Program for Selected Self-Feeding Skills for the Motorically Impaired*, 3 Am. Ass'n Educ. Severely/Profoundly Handicapped Rev. 222 (1978) 8

Bard & Fletcher, *The Right to Die*, The Atlantic Monthly 59 (Apr. 1968) 16

Bridge & Bridge, *The Brief Life and Death of Christopher Bridge*, 11 Hasting Center Rep. 17 (1981) 15

Capitol Hill Page Joe Connors Displays a Pioneering Spirit, The Albuquerque Tribune, July 26, 1985, at B-3 (Scripps Howard News Service) 20

Cassell, *Nurturing a Defective Newborn: Commentary*, 8 Hastings Center Rep. 13 (1978) 15

Clyman, Sniderman, Ballard & Roth, *What Pediatricians Say to Mothers of Sick Newborns: An Indirect Evaluation of the Counseling Process*, 63 Pediatrics 719 (1979) 13

Darling, *Parents, Physicians and Spina Bifida: A Study of Values in Conflict*, 7 Hastings Center Rep. 10 (1977) 15

Davis, *Right to Life of Handicapped (Correspondence)*, 9 J. Med. Ethics 181 (1983) 20

TABLE OF AUTHORITIES—Continued

Page

Day, Fox, et al., *The Social Competence Intervention Project: Developing Education Procedures for Teaching Social Interaction Skills to Handicapped Children*, 8 Behavioral Disorders 120 (1983) 9

Duff, *Counseling Families and Deciding Care of Severely Defective Children: A Way of Coping with "Medical Vietnam,"* 67 Pediatrics 315 (1981) 16

Duff, *Guidelines for Deciding Care of Critically Ill or Dying Patients*, 64 Pediatrics 17 (1979) .. 17

Ferleger, *Anti-Institutionalization and the Supreme Court*, 14 Rutgers L.J. 595 (1983) 8

Gerry, *The Civil Rights of Handicapped Infants: An Oklahoma "Experiment,"* 1 Issues in Law & Medicine 15 (1985) 17

Goldenberg, Nelson, Dyer & Wayne, *The Variability of Viability: The Effect of Physicians' Perceptions of Viability on the Survival of Very Low-Birth Weight Infants*, 143 Am. J. Obstet. & Gynecol. 678 (1982) 13

Gross, Cox, Tatyrek, Pollay & Barnes, *Early Management and Decision Making for Treatment of Myelomeningocele*, 72 Pediatrics 450 (1983) 17

Hentoff, *The Awful Privacy of Baby Doe*, The Atlantic Monthly 54 (Jan. 1985) 16

Herr, *Civil Rights, Uncivil Asylums, and the Retarded*, 43 U. Cinn. L. Rev. 679 (1974) 6

Herr, *The Phillip Becker Case Resolved: A Chance for Habilitation*, 22 Mental Retardation 30 (1984) 12

Horner & Keilitz, *Training Mentally Retarded Adolescents to Brush Their Teeth*, 8 J. Applied Behav. Analysis 301 (1975) 8

Johnson & Thompson, *The "Baby Doe" Rule: Is It All Bad?*, 73 Pediatrics 729 (1984) 15

Kelly & Menolascino, *Physicians' Awareness and Attitudes Toward the Mentally Retarded*, 13 Mental Retardation 10 (1975) 14

TABLE OF AUTHORITIES—Continued

Page

Krauthammer, *What to Do About 'Baby Doe,'* The New Republic 16 (Sept. 2, 1985) 17

Lancioni, *Teaching Independent Toileting to Profoundly Retarded Deaf-Blind Children,* 11 Behavior Therapy 234 (1980) 8

Lusthaus, *Involuntary Euthanasia and Current Attempts to Define Persons with Mental Retardation as Less Than Human,* 23 Mental Retardation 148 (1985) 7

Martin, Kehoe, et al., *Operant Conditioning in Dressing Behavior of Severely Retarded Girls,* 9 Mental Retardation 27 (1971) 8

McDonald, Carson, Palmer & Slay, *Physicians' Diagnostic Information to Parents of Handicapped Neonates,* 20 Mental Retardation 12 (1982) 17

McLone, *Results of Treatment of Children Born with a Myelomeningocele,* 30 Clinical Neurosurgery 407 (1983) 20

McLone, Czyzewski, Raimondi & Sommers, *Central Nervous System Infections as a Limiting Factor in the Intelligence of Children with Myelomeningocele,* 70 Pediatrics 338 (1982) 20

Murdoch, *The Psychic Treatment of Mental Defectives,* 10 J. Psycho-Asthenics 224 (1906) 6

Peterson, Austin & Lang, *Use of Teacher Prompts to Increase Social Behavior: Generalization Effects with Severely and Profoundly Retarded Adolescents,* 84 Am. J. Mental Deficiency 82 (1979) 9

Powell & Hecimovic, *Baby Doe and the Search for a Quality of Life,* 51 Exceptional Children 315 (1985) 7

Powell, Salzberg, et al., *Teaching Mentally Retarded Children to Play with Their Siblings Using Parents as Trainers,* 6 Educ. & Treatment of Children 343 (1983) 9

TABLE OF AUTHORITIES—Continued

Page

Schlein, Ash, Kiernan & Wehman, *Developing Independent Cooking Skills in a Profoundly Retarded Woman*, 6 J. Ass'n for Severely Handicapped 23 (1981) 8

Shaw, *Defining the Quality of Life: A Formula Without Numbers*, 7 Hastings Center Rep. 11 (1977) 17

Shaw, Randolph & Manard, *Ethical Issues in Pediatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons*, 60 Pediatrics 588 (1977) 14

Shurtleff, Hayden, Lowser, & Kronmal, *Myelodysplasia: Decision for Death or Disability*, 291 New Eng. J. Med. 1005 (1974) 17

Singer, *Sancity of Life or Quality of Life?*, 72 Pediatrics 128 (1983) 16

Stainback & Stainback, *A Review of the Research on the Educability of Profoundly Retarded Persons*, 18 Educ. & Training of the Mentally Retarded 90 (1983) 7

Stanovich & Stanovich, *Speaking for Themselves: A Bibliography of Writings by Mentally Handicapped Individuals* 17 Mental Retardation 83 (1979) 21

Timm & Rule, *RIP: A Cost-Effecitve Parent-Implemented Program for Young Handicapped Children*, 7 Early Child Dev. & Care 147 (1981) 11

Todres, Krane, Howell & Shannon, *Pediatricians' Attitudes Affecting Decision-Making in Defective Newborns*, 60 Pediatrics 197 (1977) 17

Upshur, *An Evaluation of Home-Based Respite Care*, 20 Mental Retardation 58 (1982) 11

Walker, Feldman, Vohr & Oh, *Cost Benefit Analysis of Neo-Natal Intensive Care for Infants Weighing Less Than 1000 Grams at Birth*, 74 Pediatrics 23 (1984) 14

TABLE OF AUTHORITIES—Continued

Page

Will, "*The Killing Will Not Stop*," The Washington Post, Apr. 22, 1982, at A29 ..... 16, 20

Wolfensberger, *The Extermination of Handicapped People in World War II Germany*, 19 Mental Retardation 1 (1981) 7

Wolraich & Siperstein, *Assessing Professionals' Prognostic Impressions of Mental Retardation*, 21 Mental Retardation 8 (1983) 14

IN THE

Supreme Court of the United States

OCTOBER TERM, 1985

No. 84-1529

MARGARET M. HECKLER, SECRETARY OF HEALTH AND HUMAN SERVICES,

Petitioner,

v.

AMERICAN HOSPITAL ASSOCIATION, *et al.*,

Respondents.

On Writ of Certiorari to the United States Court of Appeals for the Second Circuit

---

BRIEF OF *AMICI CURIAE* AMERICAN ASSOCIATION ON MENTAL DEFICIENCY, *et al.* IN SUPPORT OF PETITIONER

INTEREST OF *AMICI CURIAE*

Amici curiae are organizations of professionals who provide services, including health care, to mentally and physically handicapped people.

THE AMERICAN ASSOCIATION ON MENTAL DEFICIENCY (AAMD) is the nation's oldest and largest interdisciplinary organization of professionals in the field of mental retardation. Its members include physicians, educators, psychologists, social workers, nurses, physical and occupational therapists, specialists in communication disorders, administrators, and other professionals who serve people with mental retardation. AAMD

formally opposed the withholding of treatment on the basis of handicap as early at 1973.

THE ASSOCIATION FOR PERSONS WITH SEVERE HANDICAPS (TASH) (formerly the American Association for the Education of the Severely/Profoundly Handicapped) was founded in 1974 to develop, advocate, and implement federal statutes benefitting severely and profoundly handicapped individuals. TASH now has more than five thousand members, who include parents, physicians, educators, therapists, and other professionals. TASH has been directly involved in the issue of medical care and treatment for handicapped children. *See Legal, Economic, Psychological and Moral Considerations on the Practice of Withholding Medical Treatment from Infants with Congenital Defects* (TASH Monograph #1, 1984).

THE AMERICAN ASSOCIATION OF UNIVERSITY AFFILIATED PROGRAMS FOR THE DEVELOPMENTALLY DISABLED (AAUAP) is a national organization of university-based research, training, and model demonstration programs in the field of mental retardation. These programs employ professionals who represent all disciplines in the field of mental retardation and, among other activities, provide or assist in the provision of community-based educational, residential, vocational and health care services to people who are mentally retarded. AAUAP, along with AAMD, TASH, and other professional and voluntary organizations, is a signatory to the *Joint Policy Statement on Principles of Treatment of Disabled Infants*, which is included in the Appendix to this brief.

THE NATIONAL REHABILITATION ASSOCIATION (NRA) is one of the world's largest organizations of professionals, consumers, and other individuals devoted to improving the lives of handicapped children and adults. Founded in 1925, it has 20,000 members, the majority of whom are professionals serving physically

disabled people. The NRA has long worked for the development of programs and services that promote economic independence for the millions of persons with disabilities in this country.

The disability professionals who constitute the membership of *Amici* organizations provide mentally and physically handicapped individuals with a variety of services, including educational and medical services, and thus have abundant direct experience in this area. *Amici* wish to provide the Court with relevant information from the professional literature about recent advances in habilitation and other services for handicapped individuals and about the process by which decisions are made about medical care and treatment for newborn babies known or believed to be handicapped. The research findings and professional experience of members of *Amici* organizations support the position of Petitioner that civil rights enforcement is both appropriate and necessary to eliminate life-threatening discrimination on the basis of handicap.

The Petitioner and Respondents in this case have consented to the filing of this brief.

SUMMARY OF ARGUMENT

This case presents the narrow question of whether § 504 of the Vocational Rehabilitation Act prohibits the discriminatory withholding of appropriate medical care and treatment from newborn babies solely on the basis of their handicaps. In order to resolve this issue, it is necessary to understand the context in which Congress enacted § 504. It is also important to explore some of the contours of the debate over treating handicapped children in order to evaluate Respondents' contention that this particular form of discrimination is beyond the reach of the federal statute.

In enacting this anti-discrimination law, Congress affirmed the value of the lives of handicapped individuals.

It did so with an understanding of the advances in medicine, education, and other professions that have dramatically improved the lives of even severely handicapped people. This understanding is demonstrated not only in the text and legislative history of § 504 but also in the consistent pattern of other statutes enacted during the same period to improve services for handicapped people and to protect their civil rights. This history is totally inconsistent with the contention that Congress intended to exempt from § 504 discriminatory actions that devalue and endanger the lives of disabled children.

ARGUMENT

I. CONGRESS HAS RECOGNIZED THAT MODERN DEVELOPMENTS IN MEDICINE, EDUCATION, HABILITATION, AND OTHER SERVICES FOR NEWBORNS AND THEIR FAMILIES HAVE GREATLY ENHANCED THE LIVES OF HANDICAPPED PEOPLE.

The lives of people who are handicapped are protected by the Constitution and laws of the United States no less than those of nonhandicapped citizens. Congress, therefore, has chosen to prohibit invidious discrimination by recipients of federal funds—including the denial of life-saving medical treatment—solely on the basis of handicap. Rehabilitation Act of 1973 § 504, 29 U.S.C. § 794. This statute is part of a larger pattern of legislation designed to assist handicapped people. *See City of Cleburne v. Cleburne Living Center*, 105 S. Ct. 3249, 3256 (1985). These federal statutes have provided opportunities for education and other assistance to handicapped people and have protected their rights.[1]

---

[1] *See, e.g.*, Education of the Handicapped Act, 20 U.S.C. § 1400 *et seq.*; Developmentally Disabled Assistance and Bill of Rights Act, 42 U.S.C. § 6000 *et seq.* Congressional attempts to assist handicapped individuals date back at least to 1917. S. Rep. No. 318, 93d Cong., 1st Sess. 8, *reprinted in* 1973 U.S. Code Cong. & Ad. News

In enacting these statutes, Congress has recognized that advances in medicine, technology, special teaching techniques, and available professional services have dramatically improved the lives of handicapped citizens.[2] This

---

2076, 2082. But the most significant enactments began in the 1970s, when dramatic advances in technology and professional techniques made community integration and participation possible for millions of handicapped persons who previously had been excluded from community life. *See generally* Thompson, Wilcox & York, *The Federal Program for the Severely Handicapped: Historical Perspective, Analysis and Overview*, in *Quality Education for the Severely Handicapped* 1 (B. Wilcox & R. York eds. 1980).

[2] *See, e.g.*, the statement of Senator Randolph, debating the attempt to override the veto of the Vocational Rehabilitation Act, about persons who are severely handicapped:

> We all know of the progress that has been made in the medical profession. We know of the improvements which have been made from the standpoint of prenatal and postnatal care, resulting in higher rates of survival among our multiple handicapped infants. The changing concept of the right to treatment, the advent of new drugs and new surgical techniques, permits lives previously lost to be saved. But patients are often left with physical or mental handicaps. Once we thought the lives of such people were a loss, that we could not return them to active levels of society where they would be productive citizens. Now, however, we know that that can be done. We know it has been done.

119 Cong. Rec. 10802 (1973). Senator Cranston, debating passage of the Rehabilitation Act, stated:

> I believe that our science and technology should not be withheld from those less fortunate persons, who because of their handicaps, cannot take full advantage of much of the technology we take for granted. . . . I think that simple justice requires that we give them the benefit of a more independent, self-sufficient, and remunerative existence.

119 Cong. Rec. 24568 (1973). In the Senate Report from the Committee on Labor recommending passage of the Education for All Handicapped Children Act, the Committee recognized that "[w]ith proper education services, many [handicapped children] would be able to become productive citizens, contributing to society instead of being forced to remain burdens." S. Rep. No. 168, 94th Cong., 1st Sess. 9 (1975), *reprinted in* 1975 U.S. Code Cong. & Ad. News

acknowledgement by Congress of the potential for improving the lives of handicapped individuals informs the appropriate interpretation of § 504. First, it demonstrates the implausibility of the argument that Congress intended to exclude this particular form of discrimination from the Secretary's enforcement responsibility under § 504. In addition, it highlights the inconsistency between the Second Circuit's requirement that the Secretary continue federal funding of discriminatory health care providers and the clear purpose of the statute that no federal funds should support discrimination against handicapped persons.

Discriminatory withholding of necessary and appropriate medical care and treatment from handicapped infants is primarily based on the assumption that these children's handicaps make their lives less valuable than those of babies who have no detectable disability, and even renders them "not worth living." [3] The professional experience of

---

1425, 1433. The same report emphasizes that Congress placed the highest priority on educating the most severely handicapped children. *Id.* at 22, 1975 U.S. Code Cong. & Ad. News at 1446.

[3] The history of our society's treatment of handicapped people, which has been described by five members of this Court as "grotesque," *City of Cleburne v. Cleburne Living Center*, 105 S.Ct. 3249, 3262 (1985) (Stevens, J., concurring), 105 S.Ct. at 3266 (Marshall, J., concurring in part and dissenting in part), includes numerous suggestions that the lives of handicapped people should not be protected. *See, e.g.*, reference to proposed Iowa legislation in 1906 for "removal by the chloroform route," and the statement that "the two things are in line[:] . . . . the authority of the law to prevent defectives from being born, and the authority of the law to put them out of the world after they are born." Murdoch, *The Psychic Treatment of Mental Defectives*, 10 J. Psycho-Asthenics 224 (1906). *See also* Johnson, *Discussion on the Care of the Feebleminded and the Epileptic*, in *Proceedings of the National Conference of Charities & Corrections* 410-11 (1901), *quoted in* Herr, *Civil Rights, Uncivil Asylums, and the Retarded*, 43 U. Cinn. L. Rev. 679, 697-98 (1974) ("I do not think that to prevent the propagation of this class it is necessary to kill them off or resort to the knife; but, if it is necessary, it should be done."). *Cf.* Alexander, *Medical Science Under*

the members of *Amici* in a variety of disciplines belies this premise.[4]

Education is one of the areas in which the most dramatic developments have taken place in the last fifteen years. Before 1970, public schools routinely excluded mentally[5] and physically[6] handicapped children. This practice has been almost completely eradicated by enforcement of the Education of the Handicapped Act, 20 U.S.C. § 1400 *et seq.* This statutory right to an education has been accompanied by extraordinary advances in the instructional technology available for the education of even the most severely handicapped children.[7] It can now be stated categorically that all handicapped children can benefit from an education.[8]

Dictatorship, 241 New Eng. J. Med. 39, 40 (1949); Wolfensberger, *The Extermination of Handicapped People in World War II Germany*, 19 Mental Retardation 1 (1981). On occasion, the rhetoric in the modern debate on "quality of life" is uncomfortably reminiscent of its antecedents in American history. *See infra* note 30.

[4] *See* Lusthaus, *Involuntary Euthanasia and Current Attempts to Define Persons with Mental Retardation as Less than Human*, 23 Mental Retardation 148 (1985); Powell & Hecimovic, *Baby Doe and the Search for a Quality of Life*, 51 Exceptional Children 315 (1985).

[5] *See Pennsylvania Ass'n for Retarded Children v. Commonwealth of Pennsylvania*, 334 F. Supp. 1257 (E.D. Pa. 1971), 343 F. Supp. 279 (E.D. Pa. 1972). *See also Board of Education v. State*, 47 Ohio App. 417, 191 N.E. 914 (1934); *Watson v. City of Cambridge*, 157 Mass. 561, 32 N.E. 864 (1893).

[6] *See, e.g., State ex rel. Beattie v. Board of Education*, 169 Wis. 231, 172 N.W. 153 (1919).

[7] *See, e.g.*, Stainback & Stainback, *A Review of the Research on the Educability of Profoundly Retarded Persons*, 18 Educ. & Training of the Mentally Retarded 90 (1983); Personnel Training Program for the Education of the Severely Handicapped, *Educational Technology for the Severely Handicapped: A Comprehensive Bibliography* (1975).

[8] *See, e.g.*, Education of the Handicapped Act, 20 U.S.C. § 1400 (congressional finding).

Widely accepted teacher-training textbooks in the area include *Systematic Instruction of the Moderately and Severely Handicapped*

For children with severe disabilities, this educational opportunity now provides self-help skills that enhance their independence and thus their ability to live in the community. Children, who in another era might have lacked the ability to feed and dress themselves and care for their own hygiene, can today expect to master these skills with the assistance of special education.[9] Parallel

---

(M. Snell 2d ed. 1983); *Teaching the Severely Handicapped: Programs, Methods, and Materials* (N. Haring & L. Brown eds. 1976); W. Sailor & D. Guess, *Severely Handicapped Students: An Instructional Design* (1983); R. Gaylord-Ross & J. Holvoet, *Strategies for Educating Students with Severe Handicaps* (1985); G. Van Etten, C. Arkell & C. Van Etten, *The Severely and Profoundly Handicapped* (1980).

Amici respectfully suggest that this Court previously may have misperceived the degree of consensus among professionals on the question whether severely and profoundly mentally retarded adults and children can benefit from education and habilitation. *Cf. Youngberg v. Romeo*, 457 U.S. 307, 316-17 n.20 (1982). Methods for the education of severely and profoundly retarded individuals are universally accepted among professionals. Collectively, *Amici* encompass the broadest available spectrum of professional opinions about appropriate services for handicapped people, and can assure this Court that while disagreements exist about terminology, priorities, and particular techniques, there is no substantial professional opinion that holds severely and profoundly handicapped individuals to be incapable of benefiting from appropriately designed education and habilitation. *See* Ferleger, *Anti-Institutionalization and the Supreme Court*, 14 Rutgers L. J. 595, 628-32 (1983).

[9] *See, e.g.*, Banerdt & Bricker, *A Training Program for Selected Self-Feeding Skills for the Motorically Impaired*, 3 Am. Ass'n Educ. Severely/Profoundly Handicapped Rev. 222 (1978); Azrin & Armstrong, *The "Mini-meal"—A Method for Teaching Eating Skills to the Profoundly Retarded*, 11 Mental Retardation 9 (1973); Schlein, Ash, Kiernan & Wehman, *Developing Independent Cooking Skills in a Profoundly Retarded Woman*, 6 J. Ass'n for Severely Handicapped 23 (1981); Martin, Kehoe, et al., *Operant Conditioning in Dressing Behavior of Severely Retarded Girls*, 9 Mental Retardation 27 (1971); Horner & Keilitz, *Training Mentally Retarded Adolescents to Brush Their Teeth*, 8 J. Applied Behav. Analysis 301 (1975); Lancioni, *Teaching Independent Toileting to Profoundly Retarded Deaf-Blind Children*, 11 Behavior Therapy, 234 (1980); R. Foxx & N. Azrin, *Toilet Training the Retarded* (1973).

educational advances allow teachers to enhance a mentally disabled individual's ability to share social relationships [10] and to reduce "stereotypic" [11] and self-injurious behaviors.[12]

Handicapped children who previously would have been believed to be incapable of communication can now be taught and mechanically assisted in gaining this life skill.[13] Similarly, physical therapy and modern technological developments allow far greater mobility to many physically handicapped individuals.[14] New techniques in

---

[10] *See, e.g.*, S. McClennen, R. Hoekstra & J. Bryan, *Social Skills for Severely Retarded Adults: An Inventory and Training Program* (1980); Day, Fox, et al., *The Social Competence Intervention Project: Developing Education Procedures for Teaching Social Interaction Skills to Handicapped Children*, 8 Behavioral Disorders 120 (1983); Peterson, Austin & Lang, *Use of Teacher Prompts to Increase Social Behavior: Generalization Effects with Severely and Profoundly Retarded Adolescents*, 84 Am. J. Mental Deficiency 82 (1979); Powell, Salzberg, et al., *Teaching Mentally Retarded Children to Play with their Siblings Using Parents as Trainers*, 6 Educ. & Treatment of Children 343 (1983).

[11] *See* American Association on Mental Deficiency, *Classification in Mental Retardation* 198 (H. Grossman ed. 1983).

[12] *See, e.g.*, Hollis, *Analysis of Rocking Behavior*, in *Quality of Life in Severely and Profoundly Mentally Retarded People: Research Foundations for Improvement* 1 (C.E. Meyers ed. 1978); Baumeister & Rollings, *Self-injurious Behavior*, in 8 *International Review of Research in Mental Retardation* 1 (N. Ellis ed. 1976); *Life-Threatening Behavior: Analysis and Intervention* (J. Hollis & C. E. Meyers eds. 1982).

[13] *See, e.g.*, McDonald, *Design and Application of Communication Boards, in Non-vocal Communication Techniques and Aids for the Severely Physically Handicapped* 105 (G. Vanderheiden & K. Grilley eds. 1975); Kuntz, Carrier & Hollis, *A Nonvocal System for Teaching Retarded Children to Read and Write*, in *Quality of Life in Severely and Profoundly Mentally Retarded People: Research Foundations for Improvement* 145 (C.E. Meyers ed. 1978); Bricker, *Early Communication: Development and Training*, in *Systematic Instruction of the Moderately and Severely Handicapped* 269 (M. Snell 2d. ed. 1983).

[14] *See, e.g.*, Campbell, *Basic Considerations in Programming for Students with Movement Difficulties*, in *Systematic Instruction of*

vocational training and the availability of sheltered and competitive employment opportunities have increased the number of handicapped people who can be gainfully employed.[15]

The combination of all these developments, together with the increased accessibility of generic services which has accompanied the implementation of § 504, has made it possible for virtually all of the nation's handicapped citizens to live in their own communities.[16] This is as

---

the Moderately and Severely Handicapped 168 (M. Snell 2d ed. 1983).

[15] *See* G.T. Bellamy, D. Horner & R. Inman, *Vocational Habilitation of Severely Retarded Adults: A Direct Service Technology* (1979); Bellamy, Sowers & Bourbeau, *Work and Work-Related Services: Postschool Options*, in *Systematic Instruction of the Moderately and Severely Handicapped* 490 (M. Snell 2d ed. 1983); Rusch, *Competitive Vocational Training*, in *Systematic Instruction of the Moderately and Severely Handicapped* 503 (M. Snell 2d ed. 1983).

[16] Of the many scientific studies of this issue, perhaps the most thorough and persuasive is the one that grew out of the deinstitutionalization and imminent closure of Pennhurst. *Cf. Youngberg v. Romeo*, 457 U.S. 307 (1982); *Pennhurst State School & Hospital v. Halderman*, 465 U.S. 89 (1984). J. Conroy & V. Bradley, *Pennhurst Longitudinal Study: A Report of Five Years of Research and Analysis* (Temple Univ. & Human Services Research Inst. Mar. 1985) (finding that all Pennhurst residents—regardless of level of mental retardation—could be served successfuly in the community). *See also* K. Casey, J. McGee, J. Stark & F. Menolascino, *A Community-Based System for the Mentally Retarded: The ENCOR Experience* (1985) (describing one major metropolitan area that serves virtually all its mentally retarded citizens—regardless of level of disability—in the community); *Deinstitutionalization and Community Adjustment of Mentally Retarded People* (R. Bruininks, C.E. Meyers, B. Sigford & K.C. Lakin eds. 1981); President's Committee on Mental Retardation, *Mental Retardation: The Leading Edge—Service Programs That Work* 33-42 (11th Annual Report to the President 1979). *Dicta* from previous cases have suggested that some members of this Court may be in doubt as to whether there is a substantial sub-class of mentally retarded people who are so severely retarded that they are incapable of living and receiving services in the community. The professional experience of those

true for children as it is for adults.[17]

Of particular significance for the case at bar are the medical advances that have made it possible to save the lives and lengthen the lifespan of handicapped people[18] and, in many cases, even to reduce the level of their disability. These advances include the very treatment modalities that have been denied to handicapped children in the notorious "Baby Doe" cases. Corrective surgery for the blockage that prevents some infants with Down syndrome from digesting food has become a routine procedure. Shunting of excess fluid from babies born with hydrocephalus can greatly reduce the pressure on their brains and thus eliminate or minimize the possibility of resulting mental retardation. Surgically enclosing the sac of infants born with spina bifida can prevent infection and its attendant risk of mental disability. Orthopedic surgery can increase the mobility of many children with spina bifida. Developments in modern cardiac surgery have made it possible to correct many of the heart defects that sometimes accompany Down syndrome. *Cf. Guardianship of Phillip B.*, 139 Cal. App. 3d 407, 188 Cal. Rptr. 781 (1983).[19]

---

most directly involved in serving these individuals indicates that no such sub-class exists.

[17] The ability of children to live in the community is enhanced by the development of support services for their families, and by alternative community living arrangements for children whose families are unable to keep them at home even with additional support. *See, e.g.*, Upshur, *An Evaluation of Home-Based Respite Care*, 20 Mental Retardation 58 (1982); Timm & Rule, *RIP: A Cost-Effective Parent-Implemented Program for Young Handicapped Children*, 7 Early Child Dev. & Care 147 (1981); W. Sailor & D. Guess, *Severely Handicapped Students: An Instructional Design* 319-39 (1983).

[18] *See, e.g.*, D. MacMillan, *Mental Retardation in School and Society* 343 (2d ed. 1982).

[19] Phillip Becker, a teenager with Down syndrome, was originally denied corrective surgery for a heart defect. Following litigation,

Taken together, these developments have greatly improved the true "quality" of the lives of handicapped people. Congress's awareness of these advances has accompanied and stimulated its efforts to protect the civil rights of these citizens. This fact refutes the contention that Congress somehow intended to exclude the discriminatory withholding of life-saving medical care and treatment from the scope of its prohibition on discrimination against handicapped people. This Court should not interpret § 504 in a manner inconsistent with the policy that Congress clearly sought to implement.

II. PREDICTIONS ABOUT THE FUTURE "QUALITY OF LIFE" OF INDIVIDUAL NEWBORNS ARE NOT UNIQUELY MEDICAL JUDGMENTS IMMUNE FROM CIVIL RIGHTS LAWS.

Debates about the appropriate care and treatment of infants born with evident handicaps almost invariably turn to discussion of the prospect for the child's "quality of life." It is no surprise, therefore, that the professional literature makes it abundantly clear that the child's "quality of life" is a major factor in the decision of some health care providers to deny medical care to handicapped newborns. To understand the practice of withholding such treatment, it is necessary to review this literature about "quality of life" and the role it plays in this discriminatory practice.

Speculation about a child's future "quality of life" typically involves an insidious combination of both dubious predictions about the course of that life and subjective value judgments about what kinds of lives are worth (or not worth) living. Neither of these components is

---

the surgery was performed successfully. Herr, *The Phillip Becker Case Resolved: A Chance for Habilitation*, 22 Mental Retardation 30, 31 (1984).

uniquely within the professional expertise of physicians.[20] Thus neither is the kind of medical judgment that is beyond appropriate review for possible discrimination under the nation's civil rights laws.[21]

As the literature in the journals of health care professions demonstrates, there are significant errors and bias in the factual assumptions made by those health care providers who illegally withhold needed medical treatment.[22] For example, a substantial number of doctors who deny appropriate care and treatment to handicapped babies significantly underestimate the children's actual chances for survival if treatment were provided.[23] Physi-

---

[20] Indeed, the American Academy of Pediatrics and the other signatory organizations to the *Joint Policy Statement on Principles of Treatment of Disabled Infants* have agreed that the common components of predictions of "quality of life" are impermissible considerations in the decision about medical care and treatment. "Consideration such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decisions concerning medical care." *See* Appendix to this brief.

[21] The scope of matters believed to be within the exclusive province of physicians has varied throughout our history. *See generally* P. Starr, *The Social Transformation of American Medicine* (1982).

[22] The membership of *Amici* includes many health care providers, including numerous physicians who specialize in treating disabled individuals. It is certainly not the contention of *amici* that most health care providers or most physicians discriminate against handicapped children. But the fact that some who do withhold care and treatment on a discriminatory basis are medical professionals does not render their actions any less discriminatory. This is equally true for those health care providers who discriminate because they lack accurate information about modern prospects for the lives of handicapped individuals and for those whose actions may be motivated by a belief that the lives of handicapped people are less valuable than other lives.

[23] *See* Clyman, Sniderman, Ballard & Roth, *What Pediatricians Say to Mothers of Sick Newborns: An Indirect Evaluation of the Counseling Process*, 63 Pediatrics 719 (1979); Goldenberg, Nelson, Dyer & Wayne, *The Variability of Viability: The Effect of Phy-*

cians without practical experience with handicapped individuals are also likely to grossly underestimate what a handicapped child will be able to learn and accomplish.[24] In addition, a remarkable number lack up-to-date knowledge about the availability of community services for people with mental retardation.[25] Since pediatricians and other physicians receive very little training in the area of mental and physical disability in the course of their medical education,[26] these problems are exacerbated if the physician fails to seek consultation and assistance from professionals with experience and expertise in the relevant area of disability.[27]

---

sicians' Perceptions of Viability on the Survival of Very Low-Birth Weight Infants, 143 Am. J. Obstet. & Gynecol. 678 (1982).

[24] A recent study found that general pediatric practitioners were significantly more pessimistic about the developmental potential of mentally retarded people than professionals with more direct experience in the field. Wolraich & Siperstein, *Assessing Professionals' Prognostic Impressions of Mental Retardation*, 21 Mental Retardation 8 (1983). Another study revealed that only a small percentage of pediatric surgeons reported that their estimation of a child's potential for integration into his family was based on "acquaintance with the mental retardation literature." Shaw, Randolph & Manard, *Ethical Issues in Pediatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons*, 60 Pediatrics 588, 595 (1977). *See also infra* text accompanying notes 36-41; Walker, Feldman, Vohr & Oh, *Cost Benefit Analysis of Neo-Natal Intensive Care for Infants Weighing Less than 1000 Grams at Birth*, 74 Pediatrics 23 (1984).

[25] Kelly & Menolascino, *Physicians' Awareness and Attitudes Toward the Mentally Retarded*, 13 Mental Retardation 10 (1975). These services directly and significantly affect handicapped children throughout their lives and therefore would be a crucial component if the "quality of life" inquiry were legitimate.

[26] American Academy of Pediatrics Task Force on Pediatric Education, *The Future of Pediatric Education* (1978).

[27] "Because of the explosive increase in factual and technical knowledge, few individual physicians are now able to diagnose an infant's condition and assess accurately the child's prognosis without extensive input from other specialists. If there is one major problem in decision making for handicapped newborns, it is the

Given these substantial limitations on the information possessed by a substantial number of health care providers, it is not surprising that their decisions and the information they convey to parents are, in some cases, based on the same false stereotypes about handicapped people that remain prevalent in the population at large.[28] *See City of Cleburne v. Cleburne Living Center*, 105 S. Ct. 3249, 3267 (1985) (Marshall, J., concurring in part and dissenting in part). Indeed, parents of handicapped children still consistently report that health care providers misinformed them about the nature of their child's handicapping condition and the prospects for the child's development, education, and future.[29]

---

matter of provision of factual information." Johnson & Thompson, *The "Baby Doe" Rule: Is It All Bad?*, 73 Pediatrics 729 (1984).

[28] It was the effects of such prejudice and ignorance, of course, that § 504 was designed to correct.

[29] *See* R. Darling, *Families Against Society*, 128-45 (1979); Bridge & Bridge, *The Brief Life and Death of Christopher Bridge*, 11 Hastings Center Rep. 17 (1981); H.R. Turnbull & A. Turnbull, *Parents Speak Out: Then and Now* (2d ed. 1985). *See also Amici Curiae* brief of Association for Retarded Citizens, *et al.*

In their briefs in opposition to the writ of certiorari, Respondents attempted to persuade this Court that § 504 is inapplicable to the discriminatory denial of medical care and treatment to handicapped infants because health care providers merely make recommendations to a child's parents, who, in turn, make the final decision. This argument ignores the crucial weight that parents typically accord to the recommendations of their doctor and the unique vulnerability of parents upon being told that their newborn baby is "deformed" or "defective." *See, e.g.*, Darling, *Parents, Physicians and Spina Bifida: A Study of Values in Conflict*, 7 Hastings Center Rep. 10 (1977). The transparency of the argument that discriminatory health care providers are merely the agents of discriminatory parents is illustrated by the suggestion of one physician that parents should not be encouraged to nurture their newborn handicapped baby lest a bond be established that might cause the parents to make a "selfish" decision to order the provision of life-saving treatment, Cassell, *Nurturing a Defective Newborn: Commentary*, 8 Hastings Center Rep. 13, 14 (1978), and the admonition by a leading pediatrician that physicians who believe it to be desirable to

The other principal component of predictions about a baby's "quality of life" is a subjective judgment by the discriminatory health care provider about the value of the child's life. Discriminatory health care providers may evaluate the worth of a handicapped child's life in light of prejudices toward disabled people that do not differ in any relevant way from that of other prejudiced individuals in society.[30]

But even when a discriminatory health care provider does not openly reveal archaic stereotypes or overt prejudice, other factors reported in the professional litera-

---

withhold treatment from a child should be patient since "[f]irm rooting of a parental death wish for a defective child usually takes days, at least; and it is never free of ambivalence." Duff, *Counseling Families and Deciding Care of Severely Defective Children: A Way of Coping with "Medical Vietnam,"* 67 Pediatrics 315, 317 (1981).

[30] *See, e.g.*, Singer, *Sanctity of Life or Quality of Life?*, 72 Pediatrics 128, 129 (1983) ("If we compare a severely defective human infant with a nonhuman animal, a dog or a pig, for example, we will often find the nonhuman to have superior capacities, both actual and potential, for . . . anything . . . that can plausibly be considered morally significant."); Bard & Fletcher, *The Right to Die*, The Atlantic Monthly 59, 64 (Apr. 1968) ("[There is] no reason to feel guilty about putting a Down's syndrome baby away, whether it's 'put away' in the sense of hidden in a sanitarium or in a more responsible lethal sense. . . . True guilt arises only from an offense against a person, and a Down's is not a person. . . . Guilt over a decision to end an idiocy would be a false guilt, and probably unconsciously a form of psychic masochism.").

As in other areas of indivious discrimination, terminology can be a means of affirming or devaluing the lives of handicapped people. Those who would not acknowledge the full humanity of handicapped babies seem particularly fond of the term "defective," either as a noun or adjective, which may connote a poorly manufactured product that can be discarded. Far worse are references to handicapped children as "vegetables." For eloquent criticism of this usage, see Hentoff, *The Awful Privacy of Baby Doe*, The Atlantic Monthly 54, 57 (Jan. 1985). *See generally*, G. Will, *"The Killing Will Not Stop,"* The Washington Post, Apr. 22, 1982, at A29.

ture indicate illegal discrimination against handicapped children. Numerous recent studies and surveys indicate that some physicians weigh social and economic factors in deciding whether to recommend that routine medical care be withheld from a handicapped infant.[31] The contemporary literature contains several examples of proposed guidelines for the withholding of care that include such factors.[32] A particularly offensive example of the implementation of these suggestions by a recipient of federal funds is the pseudo-experimental triage of spina bifida babies described in the *Amicus* brief of Carlton Johnson.[33] Consideration of these non-medical factors means that life-or-death treatment decisions may be made on the basis of the wealth or education of a child's parents or the attributes of the community in which he is born.[34]

---

[31] *See, e.g.*, Affleck, *Physicians' Attitudes Toward Discretionary Medical Treatment of Down's Syndrome Infants*, 18 Mental Retardation 79 (1980); McDonald, Carson, Palmer & Slay, *Physicians' Diagnostic Information to Parents of Handicapped Neonates*, 20 Mental Retardation 12 (1982); Todres, Krane, Howell & Shannon, *Pediatricians' Attitudes Affecting Decision-Making in Defective Newborns*, 60 Pediatrics 197 (1977); Duff, *Guidelines for Deciding Care of Critically Ill or Dying Patients*, 64 Pediatrics 17, 20 (1979).

[32] *See, e.g.*, Shurtleff, Hayden, Lowser, & Kronmal, *Myelodysplasia: Decision for Death or Disability*, 291 New Eng. J. Med. 1005 (1974); Duff, *Guidelines for Deciding Care of Critically Ill or Dying Patients*, 64 Pediatrics 17 (1979). One author even reduced these factors to a pseudo-algebraic scheme that purports to provide a mathematical formula for weighing the child's "natural endowment," and "contributions" anticipated from both his family and his community. Shaw, *Defining the Quality of Life: A Formula Without Numbers*, 7 Hastings Center Rep. 11 (1977).

[33] *See* Gross, Cox, Tatyrek, Pollay & Barnes, *Early Management and Decision Making for Treatment of Myelomeningocele*, 72 Pediatrics 450 (1983); Gerry, *The Civil Rights of Handicapped Infants: An Oklahoma "Experiment,"* 1 Issues in Law & Medicine 15 (1985); Krauthammer, *What to Do About 'Baby Doe,'* The New Republic 16 (Sept. 2, 1985). Cf. J. Jones, *Bad Blood: The Tuskegee Syphilis Experiment* (1981).

[34] Without more, making treatment decisions on the basis of family wealth, education, or even race would not violate § 504,

Two state supreme courts have wisely concluded that speculating about the future "quality" of a person's life is a perilous endeavor. The Supreme Judicial Court of Massachusetts, in a landmark case, firmly rejected the equation of the supposed "quality" of a disabled man's life with assigning a reduced value to that life. That court declared that any presumed diminution of a mentally handicapped man's ability "to appreciate or experience life" attributed to his mental retardation could have no proper role in deciding whether he was to receive medical treatment. *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 738, 754, 370 N.E.2d 417, 432 (1977). The Supreme Court of New Jersey recently issued a similar declaration:

> [W]e expressly decline to authorize decision-making based on assessments of the personal worth or social utility of another's life, or the value of that life to others. We do not believe that it would be appropriate for a court to designate a person with the authority to determine that someone else's life is not worth living simply because, to that person, the patient's "quality of life" or value to society seems negligible. . . . More wide-ranging powers to make decisions about other people's lives, in our view, would create *an intolerable risk for socially isolated and defenseless people suffering from physical or mental handicaps.*

In re Conroy, 98 N.J. 321, ——, 486 A.2d 1209, 1232-33 (1985) (emphasis added). The devaluation of a person's life because of his handicap by withholding care and treatment that would be provided to a non-disabled individual is also a practice wholly inconsistent with the spirit and letter of § 504.

---

although other civil rights protections could be applied. But the fact that these factors are considered *only* for handicapped infants clearly indicates the kind of discrimination that § 504 was intended to address.

Amici do not mean to suggest that all possible forms of medical treatment must be provided to every handicapped newborn infant. For example, the *Joint Statement of Principles* makes clear that treatment need not be provided if it will merely prolong the process of a person's inevitable death. *See* Appendix. But that same *Joint Statement* also stipulates that it is *never* acceptable to withhold appropriate medical care and treatment solely on the basis of an individual's handicap. This is precisely the effect of acknowledging the applicability of § 504, and for this reason, the signatories of the *Joint Statement of Principles* recognized the importance of § 504 in protecting the rights of these children.[35]

Decisions to withhold medical treatment on the basis of a child's handicap, particularly when grounded in speculation about the quality of that child's future life, are not uniquely medical judgments. This is because such decisions do not rely on knowledge uniquely, or even primarily, within the possession of the medical profession. Therefore, this Court's admonition that deference is due to the professional judgments of disability professionals does not support Respondents' position in this case. *Cf. Youngberg v. Romeo*, 457 U.S. 307, 322 (1982).

A more relevant maxim is this Court's observation that in the field of disability, "courts should pay particular deference to reasonable legislative judgments." *Jones v. United States*, 463 U.S. 354, 380 n.13 (1983). Congress fully informed itself about the nature of disability and the lives of handicapped citizens before enacting § 504 and other contemporaneous legislation on behalf of handicapped people. This Court should not allow Congress's

---

[35] "The Federal Government has an historical and legitimate role in protecting the rights of its citizens. Among these rights is the enforcement of all applicable federal statutes established to prevent and remedy discrimination against individuals with disabilities, including those afforded by Section 504 of the Rehabilitation Act." *See* Appendix to this brief.

consistent, considered judgment about the value of the lives of these individuals to be overturned by the subjective, speculative opinions of others about whether those lives are "worth" living.

Deferring to Congress's judgment on this point is made all the more unobjectionable by the fact that the disabilities most frequently at issue in the "Baby Doe" cases are not as catastrophic as the general public[36] (and apparently some health care professionals) believe. Children born with Down syndrome are mentally retarded (typically at the mild or moderate level), but all can benefit from academic and vocational education and can lead full and productive lives.[37] Infants born with spina bifida will not necessarily be mentally retarded[38] and a large majority of them can lead independent lives.[39] The pres-

---

[36] The public's perception of these cases, already colored by widespread misunderstanding and fear concerning handicaps, can be further affected by journalistic accounts that reflect and exploit those fears. *See* Baer, *The Half-Told Story of Baby Jane Doe*, Colum. Journalism Rev. 35 (Nov./Dec. 1984).

[37] *See generally* N. Hunt, *The World of Nigel Hunt: The Diary of a Mongoloid Youth* (1967); G. Will, *"The Killing Will Not Stop,"* The Washington Post, April 22, 1982, at A29; *Down Sydrome: Advances in Biomedicine and the Behavioral Sciences* (S. Pueschel & J. Rynders eds. 1982). Recently, Senator John Chafee hired a teenager with Down syndrome as a congressional page. *Capitol Hill Page Joe Connors Displays a Pioneering Spirit*, The Albuquerque Tribune, July 26, 1985, at B-3 (Scripps Howard News Service).

[38] Children born with myelomeningocele who receive the medically indicated shunt (or who did not require a shunt) and who do not get infections have average IQs. McLone, Czyzewski, Raimondi & Sommers, *Central Nervous System Infections as a Limiting Factor in the Intelligence of Children with Myelomeningocele*, 70 Pediatrics 338 (1982).

[39] McLone, *Results of Treatment of Children Born with a Myelomeningocele*, 30 Clinical Neurosurgery 407 (1983). An example is an individual with spina bifida who recently received an honors degree in sociology. Davis, *Right to Life of Handicapped (Correspondence)*, 9 J. Med. Ethics 181 (1983).

ence before this Court of a number of self-advocacy groups as *Amici Curiae* in this case [40] is a further indication of the correctness of the judgment of Congress that the lives of handicapped people are valuable lives that should be protected by law.[41]

III. FEDERAL CIVIL RIGHTS ENFORCEMENT IS AN APPROPRIATE RESPONSE TO THE PROBLEM OF DISCRIMINATION AGAINST HANDICAPPED INFANTS.

This case presents the narrow question whether § 504 reaches discriminatory denial of nutrition and medical care and treatment to handicapped newborn babies. Therefore, the details of the Secretary's previous regulations are not at issue. This Court need not, and should not, consider the appropriateness of any particular regulations or techniques of enforcement.[42]

---

[40] *See also* P. Williams & B. Shoultz, *We Can Speak for Ourselves: Self Advocacy By Mentally Handicapped People* (1984); Stanovich & Stanovich, *Speaking for Themselves: A Bibliography of Writings by Mentally Handicapped Individuals,* 17 Mental Retardation 83 (1979).

[41] In popular discussion, the birth of a handicapped child is often spoken of as a "tragedy." It is indeed tragic when a child is born with a disabling condition that could have been prevented. (Many handicapping conditions can now be prevented by nutritional, dietary, and other kinds of interventions. *Amici* have been active in seeking implementation of measures to prevent this unnecessary incidence of handicaps.) But it is often said that the birth itself is a "tragedy." This view suggests a conclusion that the lives of handicapped people are worthless. Congress clearly did not view the lives of people with handicaps as valueless. Instead, it attempted, through § 504, to prevent unwarranted discrimination from adding to the burdens that handicapped people already bear. A handicapped child is, first and foremost, a child; its handicap is not the entirety of its being any more than its race or gender.

[42] If the decision of the Court of Appeals is reversed and the Secretary is permitted to promulgate regulations, *Amici* will then take the opportunity to make their views known on the details of the proposed regulations.

Amici recognize that enforcement of civil rights laws sometimes can be inconvenient and even disruptive for health care providers. For this reason, within the range of effective enforcement mechanisms, *Amici* believe that the least disruptive means should always be preferred. But the fact that enforcement of § 504 might create some inconvenience for the recipients of federal funds does not mean that Congress intended for this kind of discriminatory decision-making (or even medical care as a whole) to be exempt from the statute's requirements. Congress has long recognized that the enforcement of civil rights laws carries with it a necessary, albeit regrettable, measure of inconvenience for a variety of individuals and institutions in our society. Nevertheless, it has consistently concluded that the rights at issue were of sufficient magnitude to outweigh the burden placed on those who might be accused of discriminatory actions.[43] It certainly cannot be maintained that the stakes for a baby who may be unlawfully deprived of nutrition or life-saving medical care and treatment are smaller than in cases that involve educational placement or employment discrimination.

Equally unpersuasive is the suggestion that the enactment of the Child Abuse Amendments of 1984, Pub.L. No. 98-457, 98 Stat. 1749 *et seq.*, somehow strips § 504 of its applicability to this kind of discrimination. It should first be noted that Congress explicitly denied any such intention.[44] Further, the existence of federal en-

---

[43] *See, e.g.*, 121 Cong. Rec. 25540 (1975) (remarks of Rep. Miller on the administrative burdens of the Education of the Handicapped Act).

[44] "No provision of this Act or any amendment made by this Act is intended to affect any right or protection under section 504 of the Rehabilitation Act of 1973." Child Abuse Amendments of 1984 § 127(a), Pub. L. No. 98-457, § 127(a), 98 Stat. 1749, 1754. *See Watt v. Alaska*, 451 U.S. 259, 267 (1981) (legislative intention to repeal a statute must be clear and manifest); *Morton v. Mancari*, 417 U.S. 535, 551 (1974) ("The courts are not at liberty to pick

couragement for state remedies does not obviate the need for federal enforcement in those cases where states fail to protect the lives of handicapped children. This is not the only area of civil rights law in which state provisions parallel those in federal statutes. *Amici* do not dispute that state enforcement in individual cases of discrimination is often preferable to federal enforcement. But, as in other areas of civil rights enforcement, experience suggests that states will not be uniformly diligent in carrying out their responsibilities. Federal enforcement capability is therefore appropriate and necessary to guarantee that handicapped children are not denied protection of their right to nutrition or medical care merely because of their state of residence.

The argument that the Child Abuse Amendments somehow supplant § 504 also requires attribution to Congress of inconsistent and anomalous purposes and methods. Section 504 declares that federal funds will not be used in discriminatory ways. The Child Abuse Amendments require the withdrawal of federal funds from state child welfare agencies that do not protect handicapped children from discriminatory denial of treatment. But if the latter law were interpreted to eliminate enforcement of the former statute, the Secretary would be required to *deny* funds to the welfare agency but would be required to *continue* funding the recipient who actually engaged in the discriminatory conduct. It is well settled that statutes should not be interpreted in a way that would produce absurd results. *United States v. Turkette*, 452 U.S. 576, 580 (1981).

Amici believe that § 504 is a tool that is as essential for the protection of handicapped infants as it is for other handicapped people. Its protections are literally a matter of life and death for some of the most vulnerable of our nation's citizens.

---

and choose among congressional enactments, and when two statutes are capable of co-existence, it is the duty of the courts, absent a clearly expressed congressional intention to the contrary, to regard each as effective.").

CONCLUSION

For the reasons set forth above, *Amici* urge this Court to reverse the judgment of the Second Circuit.

Respectfully submitted,

JAMES W. ELLIS
RUTH A. LUCKASSON
1117 Stanford, NE
Albuquerque, New Mexico 87131
Counsel for Amici Curiae

Of Counsel:
H. RUTHERFORD TURNBULL, III

APPENDIX

The following Joint Statement is reprinted from 73 Pediatrics 559 (1984). *See also* 49 Fed. Reg. 1622, 1652 (Jan. 12, 1984).

JOINT POLICY STATEMENT

PRINCIPLES OF TREATMENT OF DISABLED INFANTS

Discrimination of any type against any individual with a disability/disabilities, regardless of the nature or severity of the disability, is morally and legally indefensible.

Throughout their lives, all disabled individuals have the same rights as other citizens, including access to such major societal activities as health care, education, and employment.

These rights for all disabled persons must be recognized at birth.

NEED FOR INFORMATION

There is a need for professional education and dissemination of updated information which will improve decision-making about disabled individuals, especially newborns. To this end, it is imperative to educate all persons involved in the decision-making process. Parents should be given information on available resources to assist in the care of their disabled infant. Society should be informed about the value and worth of disabled persons. Professional organizations, advocacy groups, the government, and individual care givers should educate and inform the general public on the care, need, value, and worth of disabled infants.

MEDICAL CARE

When medical care is clearly beneficial, it should always be provided. When appropriate medical care is not

available, arrangements should be made to transfer the infant to an appropriate medical facility. Consideration [sic] such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decisions concerning medical care. The individual's medical condition should be the sole focus of the decision. These are very strict standards.

It is ethically and legally justified to withhold medical or surgical procedures which are clearly futile and will only prolong the act of dying. However, supportive care should be provided, including sustenance as medically indicated and relief of pain and suffering. The needs of the dying person should be respected. The family also should be supported in its grieving.

In cases where it is uncertain whether medical treatment will be beneficial, a person's disability must not be the basis for a decision to withhold treatment. At all times during the process when decisions are being made about the benefit or futility of medical treatment, the person should be cared for in the medically most appropriate ways. When doubt exists at any time about whether to treat, a presumption always should be in favor of treatment.

GOVERNMENT AND COMMUNITY SUPPORT

Once a decision to treat an infant has been made, government and private agencies must be prepared to allocate adequate resources for appropriate services as needed to child and family for as long as needed. Services should be individualized, community-based, and coordinated.

The Federal Government has an historical and legitimate role in protecting the rights of its citizens. Among these rights is the enforcement of all applicable federal statutes established to prevent and remedy discrimina-

tion against individuals with disabilities, including those afforded by Section 504 of the Rehabilitation Act. States also have legitimate roles in protecting the rights of their citizens and an obligation to enforce all applicable state laws.

SIGNATORIES

American Academy of Pediatrics (AAP)
Paul F. Wehrle, President

Association for Retarded Citizens (ARC)
Joseph A. Buonomo, Past President

The National Association of Children's Hospitals and Related Institutions, Inc. (NACHRI)
Robert H. Sweeney, President

Spina Bifida Association of America
Kent Smith, Executive Director

The Association for Persons with Severe Handicaps (TASH)
H.D. Fredericks, President

American Association on Mental Deficiency (AAMD)
Herbert Grossman, President

American Association of University Affiliated Programs for Persons with Developmental Disabilities (AAUAP)
Alfred Healy, President

American Coalition of Citizens with Disabilities, Inc. (ACCD)

Eunice K. Fiorioto, Past President

National Down's Syndrome Congress
Thomas J. O'Neill, President

Nov. 29, 1983
Capitol Holiday Inn, Washington, DC